# North Central London CCG LeDeR annual report 2019-2020

# Contents



## 1.0 Introduction

This is the first combined North Central London CCG Learning Disability Mortality Review (LeDeR) annual report on the reviews of deaths of people with a learning disability.

The LeDeR programme reports on deaths of people with a learning disability aged 4 years and over, the definition used is that in 'Valuing people' (2001)[1] and includes the presence of:
*"a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development".*

LeDeR was established to support local areas in reviewing the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement. It was implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017.

The programme has developed a process for reviewing the deaths of people with learning disabilities. All deaths receive an initial review; those where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, receive a full multi-agency review of the death.

The LeDeR programme aims to positively influence practice and policy by:

- Identifying potentially avoidable contributory factors related to deaths of people with learning disabilities
- Identifying variation and best practice in preventing premature mortality of people with learning disabilities
- Developing action plans to make any necessary changes to health and social care service delivery for people with learning disabilities

## 2.0 NCL LeDeR Structure and Governance

The LeDeR programme is administered and managed by Bristol University on behalf of NHS England. The NHS Long Term Plan[2] (January 2019) sets out the objective for people with a learning disability, autism or both to lead longer, happier and healthier lives. In North Central London (NCL), the LeDeR programme sits within the Learning Disabilities (LD) and Autism Programme, which, in line with the expectations set out in the Long Term Plan, also includes:

- The continued reduction of inpatient bed use and prevention of hospital admission
- Annual Health Checks in primary care for people with learning disabilities
- STOMP and STAMP (Stopping over medication of people with a learning disability, autism and Supporting Treatment and Appropriate Medication in Paediatrics)

The Senior Reporting Officer for the LD & Autism Programme is Paul Sinden, Chief Operating Officer, NCL CCG. The Programme Board meets bi-monthly, and includes senior representation

[1] Dept of Health (2001) valuing people: a new strategy for Learning Disabilities for the 21st Century
[2] https://www.longtermplan.nhs.uk/

from NCL Health and Social Care partners, Mental Health Trusts, NHS England and Parent Carer representatives. It provides strategic oversight of the programme and holds Member organisations accountable for performance against the NHS Learning Disabilities and Autism Long Term Plan objectives and trajectories at both an NCL and regional level. The Programme Board is accountable to NHS England for achievement of the programme milestones and targets, which are monitored via regular assurance meetings. This also included the LeDeR NHS Operational and Planning guidance for 2019/20 (see appendix 1)

From 2020/21, a restructure of NCL CCG will lead to some changes in the governance of the LeDeR Programme, which will include a reporting line into the NCL Quality function. This is expected to further support the delivery of the LeDeR Programme across NCL.

Key processes to deliver mortality reviews of people with learning disabilities have been well established across NCL. Each borough has a local LeDeR steering group chaired by a Local Area Contact (LAC) who is also part of the wider North Central London LeDeR Steering group.

An NCL LeDeR coordinator has been employed since January 2019 to support the delivery of the programme

Within each NCL borough the LACs are:

**Islington**: David Pennington Designated Professional Safeguarding Adults
**Haringey**: Beverly Mukandi, Head of Quality Improvement
**Camden**: Sarah Phillip, Designated Professional Safeguarding Adults
**Barnet**: Sue Tomlin, Head of Joint Commissioning Learning Disabilities and Physical & Sensory Impairment
**Enfield**: Chris O'Donnell, Person Centred Planning Coordinator
Christina Keating, Designated Professional Safeguarding Children, NCL Child Death Overview Panel Lead

LAC responsibilities include:

- chairing of borough LeDeR steering group
- identifying and organising the training of local reviewers
- receiving notifications of deaths and allocating cases to local reviewers
- providing advice and support for local reviewers as required
- quality assure reviews that have been completed submitting these to the LeDeR system
- collating learning points and recommendations
- sharing learning with health and social care providers
- highlighting and escalating any systemic learning to NCL LeDeR steering group

When a LeDeR review has been conducted and a person's death indicates significant concerns or failings in care and support, the review is referred to statutory safeguarding processes and may be placed on hold within the LeDeR system pending the outcome for further enquiry.

All LeDeR reviews of child deaths are undertaken by the Child Death Overview Panel (CDOP) who shares their report on every child with a learning disability with the local LeDeR programme. The

CCG's lead nurse for CDOP sits on both the child death panel and the NCL LeDeR steering group to ensure links between the two are maintained.

A significant amount of work has taken place to raise LeDeR's profile across NCL including

- information on GP intranets and community learning disability teams' websites on how to report a death
- voluntary sector representatives attend steering groups
- communications to care providers on importance of engaging in process as well as themes and learning
- producing an NCL LeDeR newsletter to highlight learning and actions taken as a result
- raising awareness via GP and staff bulletins
- borough based presentations to discuss LeDeR findings and learning to encourage more staff to become reviewers from a wide range of specialities

In March 2020 NCL LeDeR steering group hosted a LeDeR reviewers' network forum to enable networking and discussion around shared experiences of LeDeR and learning from reviews. Feedback was positive with a possible future session planned focusing on working with bereaved families. We would like to extend our sincere thanks to our guest speaker Stuart Hasler for attending and sharing his experiences on creating a personal admission plan, which helped save his life.

## 3.0 Deaths notified to North Central London CCG 2019/20

### 3.1 Number of deaths

| Year | Number of deaths notified | Completed | Female | Male |
|---|---|---|---|---|
| 2016/2017* | 6 | 6 (100%) | 2 | 4 |
| 2017/2018 | 43 | 36 (84%) | 19 | 24 |
| 2018/2019 | 51 | 34 (67%) | 24 | 28 |
| 2019/2020 | 71 | 23 (32%) | 33 | 38 |
| **Total** | **171** | **99 (58%)** | **78** | **94** |

**Table 1 – notifications to NCL**
***Camden were the only borough receiving notifications at this time**

Camden was a LeDeR programme pilot site in 2016. More notifications have been received as other boroughs followed, forming steering groups and embedding processes for training reviewers and allocating reviews. The most significant challenge to the delivery of the programme to date has been the rate at which mortality reviews are being completed. Barnet and Enfield have some of the highest notification numbers for a single borough in the London region and have a number of backlogged reviews. Both boroughs have a large number of supported living and residential accommodation for those with learning disabilities.

In 2018/2019 NHS England provided short term funding to enable NCL to establish a pool of independent LeDeR reviewers to support the completion of backlog reviews. Given the large number of notifications received by both Barnet and Enfield it has proved challenging to complete reviews within the required timeframe.

## 3.2 Notifications by month

| NCL Borough | Apr | May | Jun | July | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Barnet | 2 | 3 | 1 | 2 | 2 | 2 | 4 | 2 | 1 | 1 | 4 | 5 | 29 |
| Camden | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 3 | 0 | 0 | 5 |
| Enfield | 1 | 2 | 2 | 2 | 2 | 1 | 0 | 0 | 1 | 4 | 1 | 4 | 20 |
| Haringey | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 1 | 2 | 0 | 2 | 7 |
| Islington | 0 | 1 | 0 | 0 | 0 | 2 | 1 | 1 | 2 | 0 | 1 | 2 | 10 |
| **Total** | **3** | **6** | **3** | **4** | **5** | **7** | **6** | **3** | **5** | **10** | **6** | **13** | **71** |

**Table 2- notifications by month, 2019/20**

The notifications of death indicate seasonal variation with Q4 (winter) accounting for 41% of LeDeR deaths. Deaths within Barnet and Enfield account for 69% of all notified deaths in 2019/20.

## 3.3 Number of Deaths by Gender

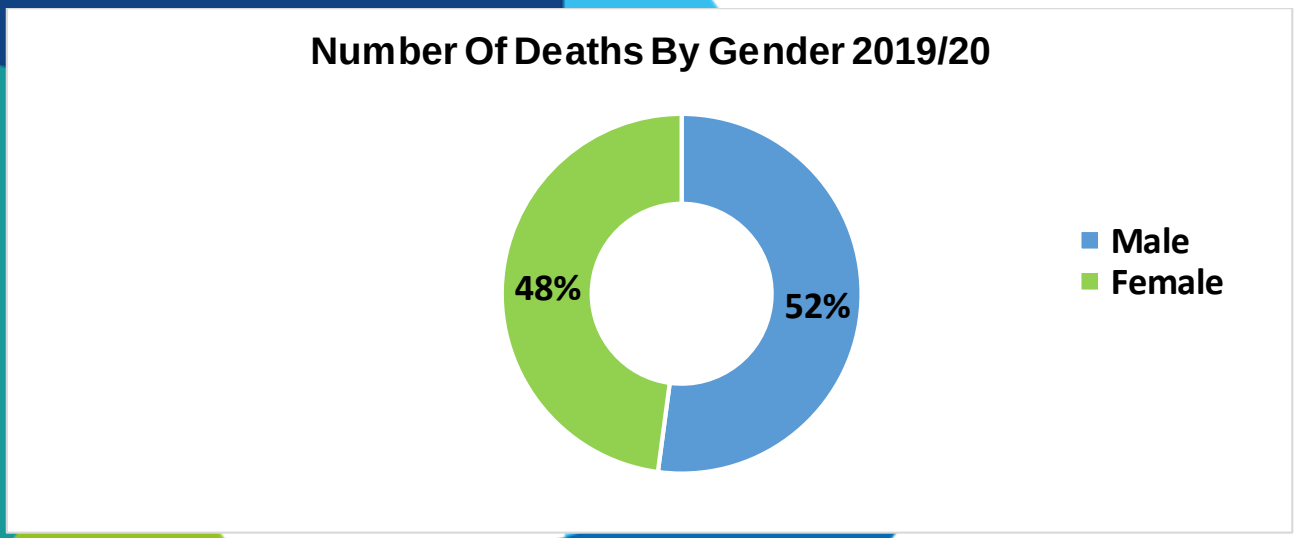



**Figure 1- number of death by gender**

Figure 1 indicates that male and female deaths reported to NCL in 2019/20 were largely equal, with men being reported slightly higher. This is similar to what has been reported nationally.

## 3.4 Age at death

| Age | Number | Percentage |
|---|---|---|
| 0-9 | 1 | 1% |

| | | |
|---|---|---|
| 10-19 | 6 | 8% |
| 20 - 29 | 4 | 6% |
| 30 - 39 | 6 | 8% |
| 40 – 49 | 4 | 6% |
| 50 – 59 | 8 | 11% |
| 60 - 69 | 15 | 22% |
| 70 - 79 | 17 | 24% |
| 80 - 91+ | 10 | 14% |

**Table 3- age at death, 2019/20**

Within NCL the over 60 age group accounts for 60% of the deaths in NCL, with the over 70 age group representing 38% of deaths within NCL. Nationally, for deaths notified in 2019, the median (average) age at death was 61 for males and 59 for females, an increase of 1 year for males since 2018.

| | Median age of death 2019/2020 | | | | | |
|---|---|---|---|---|---|---|
| **Gender** | **Camden** | **Islington** | **Haringey** | **Barnet** | **Enfield** | **National** |
| **M** | 59 | 67 | 70 | 58 | 68 | 61 |
| **F** | 55 | 71.5 | 50 | 57 | 71 | 59 |

**Table 4- NCL and National median age of death by gender**

## 3.5 Place of Death

Across NCL there were more deaths in hospital (53%) than usual place of residence (42%) 5% died in places such as hospice/palliative care unit or the home of a relative or friend.

Nationally the proportion of people with learning disabilities dying in hospital was 62%, compared to the general population where it is 46%.

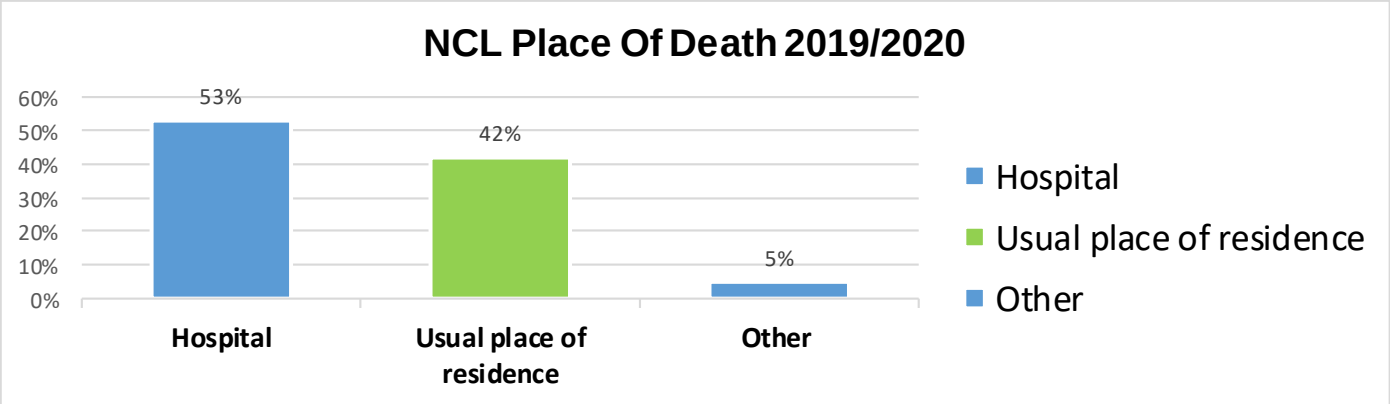



**Table 5- place of death**

Reviews have indicated a relatively high number of people who died within 2 weeks of discharge. Some of this is due to improved end of life care planning, however, issues with information sharing on discharge have emerged from reviews. A significant amount of work has been undertaken with acute providers on implementing accessible discharge packs to improve this.

## 3.6 Ethnicity

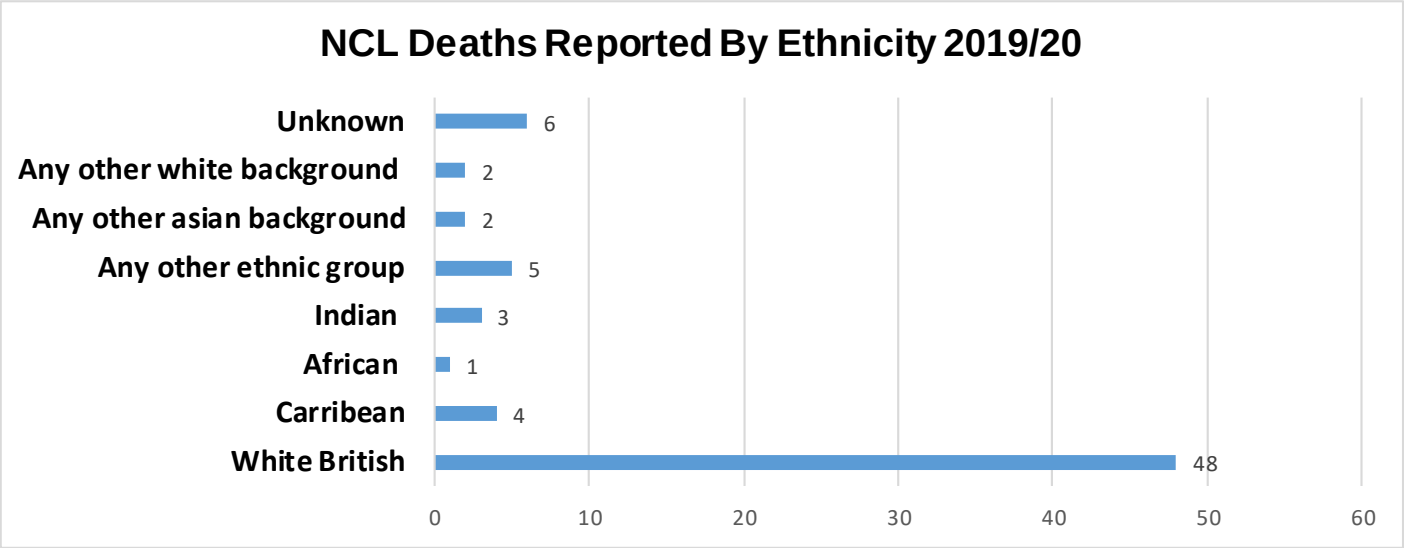



**Table 6- Deaths Reported by Ethnicity 2019-20**

An individual's ethnicity was reported for 65 of the 71 deaths notified in 2019/2020 and reporting shows that people who identify as White British make up the highest proportion of deaths for this reporting year. Barnet, which reported the highest number of notifications, sees the White ethnic group[3] make up 59.7% of the borough's population, while the proportion of Black, Asian and Minority Ethnic (BAME) people in the borough is 40.3%[4]. This is in line with the demographics of the population in the borough. Enfield reported a trend of lower mortality amongst BAME groups. We will continue to monitor this as a steering group.

## 3.7 Causes of Death

| Cause Of Death | Number | % |
|---|---|---|
| Respiratory related- including aspiration pneumonia | 21 | 42% |
| Cardiovascular related | 7 | 14% |
| Cancer (Ovarian, Oesophageal, Breast, Urethral) | 6 | 12% |
| Sepsis | 5 | 10% |
| Brain injury | 3 | 6% |
| Covid 19 | 2 | 4% |
| Systemic Cardida Infection | 2 | 4% |
| Life limiting condition | 2 | 4% |
| Traumatic Sub-Arachnoid Haemorrhage | 1 | 2% |
| Multiple Organ Failure | 1 | 2% |

**Table 7- Causes of death reported 2019/2020**

Causes of death for completed reviews are taken from the primary cause of death listed on the death certificate which is documented as part of the review. As many reviews have had delayed completion, some reviews were reported in 2018/2019.

This report reflects the position at the end of March 2020 and at the time of writing it is believed that 2 people with a learning disability have died as a result of COVID19 or it was a contributory

[3] White British, White Irish, Other White
[4] https://jsna.barnet.gov.uk/1-demographyv

factor in their death. The impact that COVID19 has had on the learning disability population will be reported in the coming year.

The Leder National report stated that in 2019 the most common causes of death reported are: pneumonia (24%) and aspiration pneumonia (16%). This is similar to 2018. Sepsis (7%) and epilepsy (6%) were also reported as causes of death.

A significant proportion of deaths reviewed across NCL in 2019/2020 were associated with respiratory problems, similar to deaths reports in 2018/2019 in keeping with national findings. Enfield have undertaken significant work over the last few years to support people diagnosed with Dysphagia. This has coincided with a slight decrease in relative mortality rate and slight increase in median age at death of those who died of respiratory conditions.

## 4.0 Themes, learning points and recommendations from reviews

Themes from reviews identified by local steering groups have included:

- Continued focus needed on promotion of annual health checks and additional support to take part in annual health checks
- Need to ensure reasonable adjustments are made within services accessed by people with a learning disability
- Recognition of early warning signs of ill health
- Need for a consistent Multi-disciplinary (MDT) approach to managing a patient's risk due to complex physical and mental health
- Staff across all settings to develop competency in supporting clients who make unwise decisions and self-neglect, particularly with regard to individuals who have fluctuating capacity
- Clear documentation of capacity assessments and best interests decisions in GP and hospital records
- End of life planning should be discussed as early as possible, supported by active conversations about death and dying

## 5.0 Service improvements

There has been some shared and individual service improvements across NCL in response to the learning from reviews.

**Shared Improvements**

- All areas promoted the 'STOP and Watch' guidance to identify the early signs of ill health in those with a learning disability (see Appendix 1)
- Improving mouthcare practice focused session- NCL steering group linked in with work Camden & Islington Foundation NHS Trust produced around mouthcare and its link to aspiration pneumonia. Materials were circulated across Learning disability teams

- Strengthened links with learning disability acute nurses across the system with an improvement in awareness raising/training amongst staff within local acute trusts
- Easy read discharge pack developed by the London A2A (Access to Acute) learning disability liaison nurse network is used for those with learning disabilities discharged from the Royal Free Hospital Trust. A quality improvement project is planned for 2020/2021 to further embed this.

**Individual service improvements have included:**

**Camden**

- **Healthintent**: learning disabilities has been selected as one of the Healthintent population management workstreams- this will allow health and care professionals in North Central London to be more proactive in the care of patients and communities

- **Significant 7**: Camden Learning Disability Service (CLDS) successfully piloted this innovative training tool for care homes to prevent avoidable A&E attendances and acute admissions for complex and frail patients

- **Films:** created by Royal Free Hospital to improve patient experience by educating hospital staff about patients with learning disabilities

- **Coordinate My Care**: Camden are progressing uploading patient care plans for those with learning disabilities who have complex needs with other NCL boroughs looking at the option of implementing this

- **Self-neglect tool kit**[5]: multiagency self-neglect tool kit has bene developed to include supporting individuals with a learning disability

**Enfield**

- **Engagement**: North Middlesex Hospital has a Learning Disabilities Steering Group that has excellent engagement from peer advocates where learning from reviews are discussed

- **End of Life Care Steering group**: held End of Life Care Planning workshops for people with learning disabilities to support them to begin developing their own End Of Life Care plans. The learning from previous sessions were published in the British Journal of Learning Disabilities November 2019 edition[6]

- **Death Cafe:** a Learning Disability specific 'Death Café' was held using NCL funding following learning from LeDeR reviews. Three cafes were held in 2019 which were well attended with positive feedback

**Islington**

[5] https://www.camden.gov.uk/documents/20142/0/SAPB+Multi-Agency+Self-Neglect+Toolkit+November+2019.docx/6af8595b-ac40-7d5d-2a30-954ce732aa3d?version=1.0.
[6] https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12317?af=R

- **Outreach Flu Jab Service**: Islington Learning Disability Partnership (ILDP) is offering Outreach Flu Jab Service to under 65s with a learning disability

- **GP liaison service:** to support practices to support those to attend for annual health checks

- **Easy read sepsis**: information guide to help those with learning disabilities recognise the signs (see appendix 2)

- **Films**: created through a local advocacy group Centre 404 to inform families on LeDeR process and organisations that can support them

- **End of Life**: as a result of learning from reviews an easy read planning template was created

**Haringey**

- **Blood test pathway project between Barnet and Haringey on improving access to diagnostic testing:** this followed 20 people needing a simple blood test over a 6 month period to understand the barriers they faced were and as an outcome, designed a joint pathway to support people to overcome those barriers

- **Complex Care Pathway:** is being developed to reduce the risk of hospital admissions, helping to maintain and improve health and quality of life for adults with learning disabilities

**Barnet**

- **LeDeR champion work**: a role created within GP practices to increase joint working

- **My Health Matters Folder**: is Barnet's health action plan. A health promotion event takes place yearly with 2019/20 focusing on mental health

- **Starting the Conversation**: End of Life information pack was created for family or care providers in how to talk about death and dying with people with learning disabilities

- **Admissions and Discharges meeting**: a weekly 'huddle' meeting where lead health staff review all physical health admissions to hospital to ensure discharge planning is timely

- **Cancer**: learning disability team have worked closely with the Cancer clinical lead to produce a series of easy read screening invite letters

## 6. Priorities for 2020/2021

NCL continues to be committed to deliver the LeDeR programme. During the past year our reviewers have managed competing priorities to deliver thorough reviews. The impact of the Covid pandemic has been significant on professional's ability to progress reviews and there are still a

number of reviews to be completed. These remain a priority. The NCL LeDeR steering group will continue to lead on implementing learning locally, and will support more people to train to become reviewers.

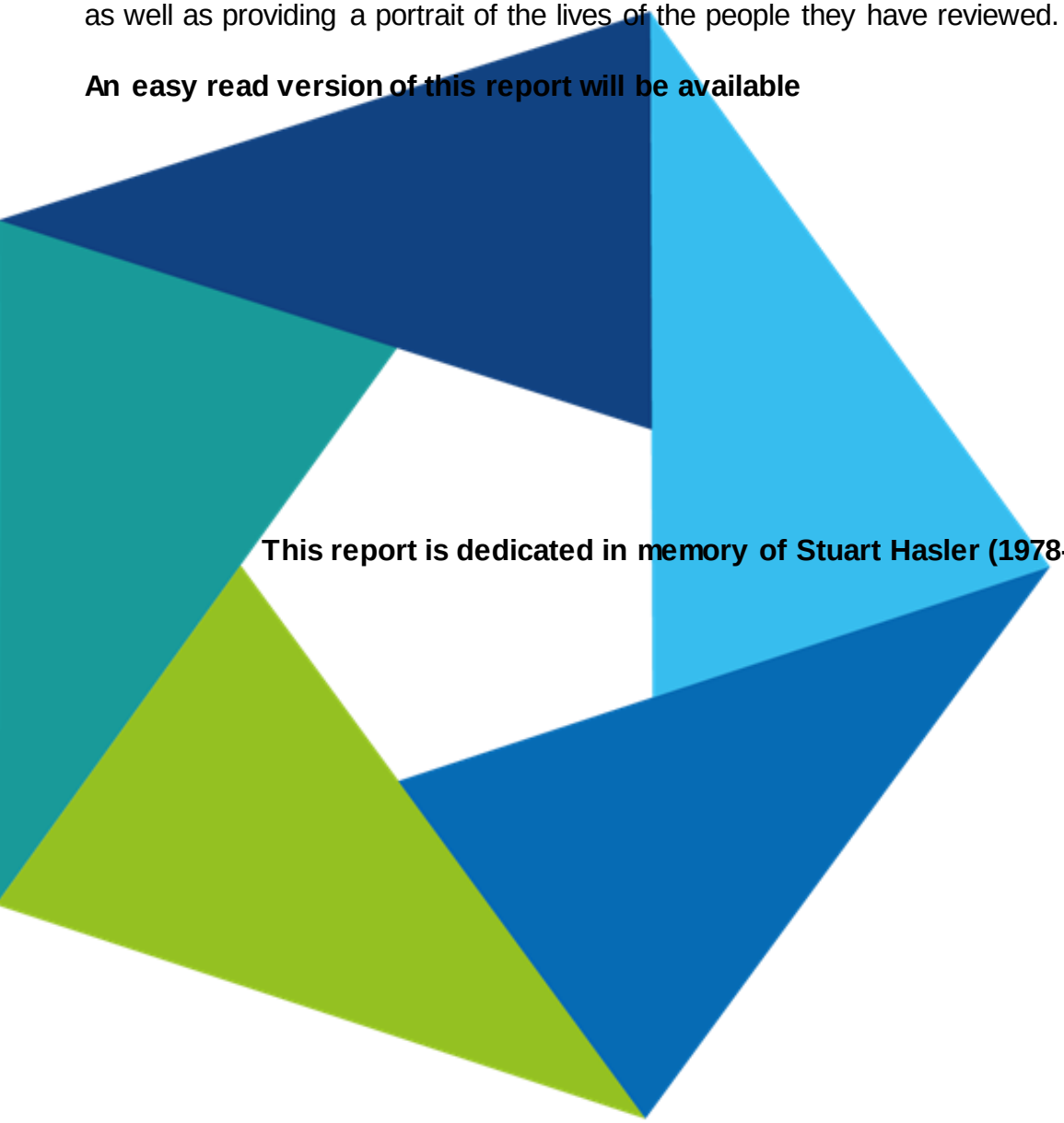
Moving forward it is the intention of the NCL LeDeR steering group to host an overall action plan. The intention is to develop this plan in Q4 2020/21, following completion of outstanding reviews from 2019/20 and Q1 2020/21, which will also include additional deaths that have occurred as a result of the Covid pandemic. This will help to identify themes and opportunities across NCL, helping us to maximise the use of resources. Initial themes we plan to focus on include:

- End of life
- Annual health checks
- Mental Capacity Act
- Shared records

Acknowledgments:

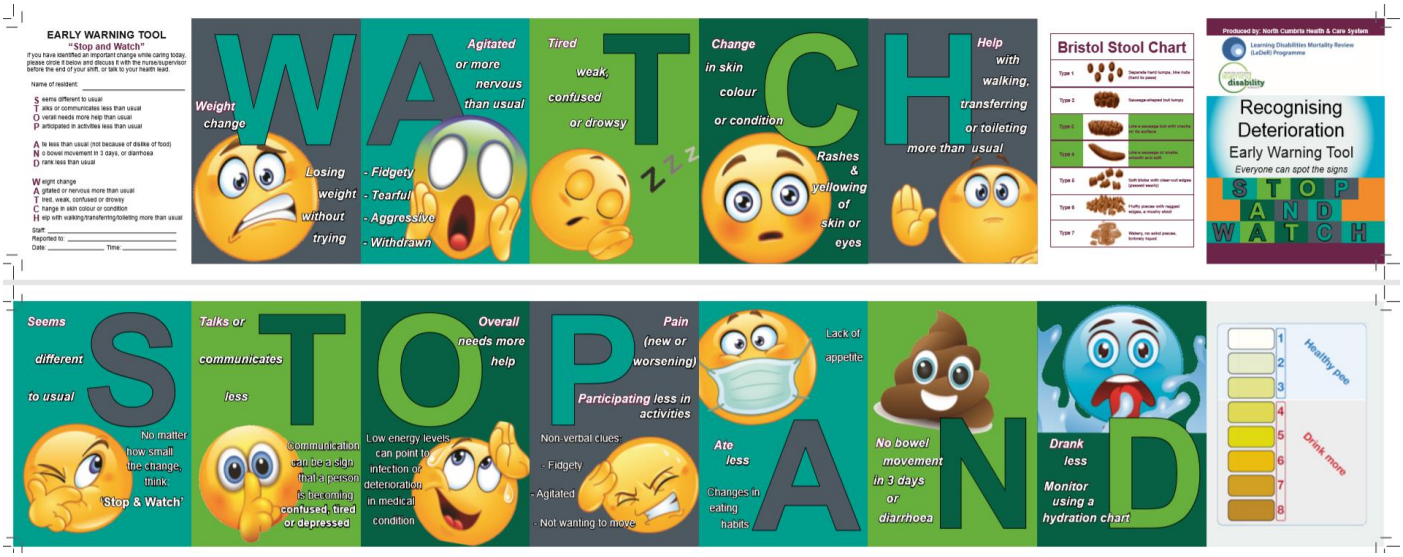
The authors would like to extend their thanks to the all of the reviewers who have contributed to the LeDeR reviews, it should be noted that undertaking these reviews has usually been in addition to their day to day work. The LeDeR reviews reflect a great deal of analysis and detective work on behalf of the reviewers, they have each brought to life the circumstances leading up to the death, as well as providing a portrait of the lives of the people they have reviewed.

**An easy read version of this report will be available**

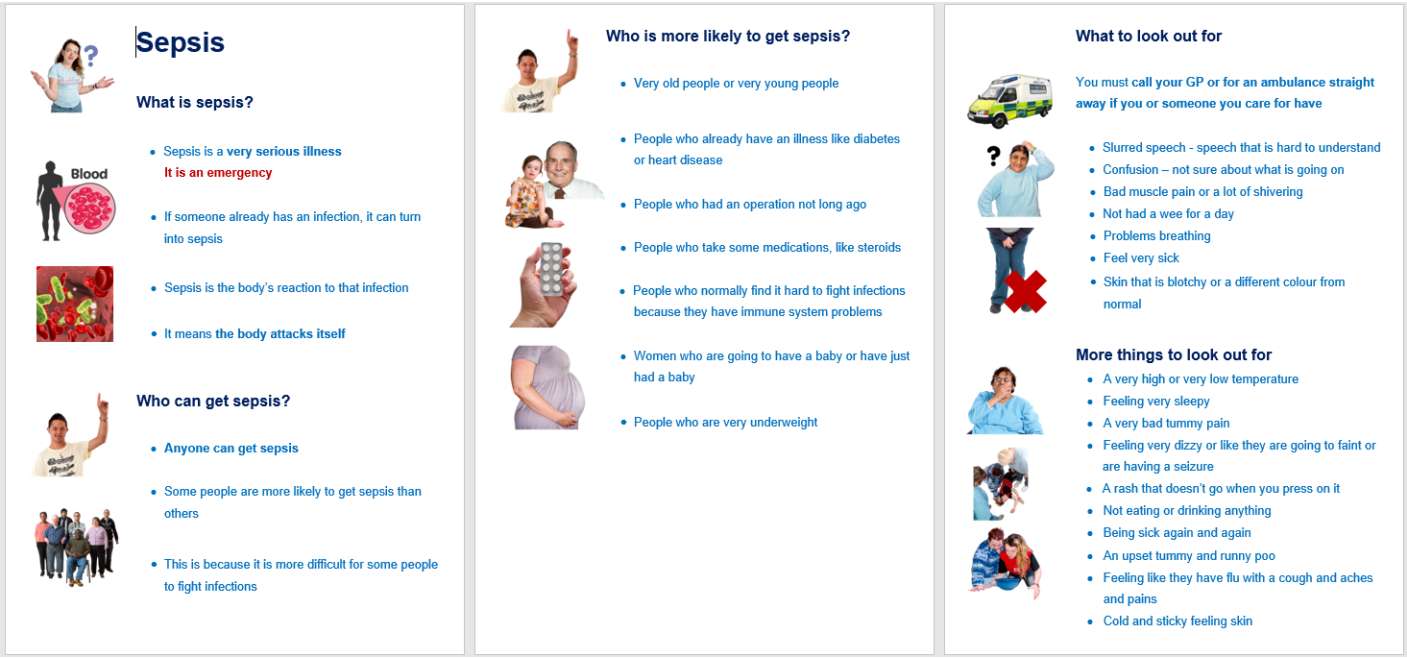


**This report is dedicated in memory of Stuart Hasler (1978-2020)**

## Appendix 1 Stop and Watch early warning signs tool




## Appendix 2



**Appendix 3**

The NHS Operational and Planning guidance for 2019/20 sets out the actions CCGs need take and is updated every year.

In 2019 there were 4 areas CCGs had to demonstrate when assessing local delivery of the LeDeR programme

| **Statements in the NHS 2019/20 Operating Planning and Contracting Guidance** | **North Central London's position** |
|---|---|
| CCG's are a member of a Learning from Deaths report (LeDeR) Steering Group and have a named person with lead responsibility | There has been an NCL wide steering group in place since 2017/2018 during 2019/2020. Each borough has a local LeDeR steering group chaired by the Local Area Contact |
| CCGs needed to have a robust plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area. | NCL have a LeDeR coordinator in place to support reviewers and Local Area Contacts to progress reviews in each borough.<br><br>In March 2020, the full LeDeR review process slowed due to Covid-19. Capacity across teams reduced as people were redeployed, and information became more difficult to obtain due to system wide capacity reduction. Each borough has a recovery plan in place and aim to complete all outstanding reviews notified prior to June 2020 by November 30 2020. |
| CCG has systems in place to analyse and address the themes and recommendations from completed LeDeR reviews | NCL have robust systems in place to analyse and address the themes and recommendations from completed reviews in a timely manner. Each borough has an action plan in order to monitor actions taken in response to findings |
| An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews | Each borough completed a LeDeR annual report for 2018/19. This is the first NCL LeDeR annual report for 2019/20. It will be submitted to the NCL Quality and Safeguarding Committee before being published on the CCG public facing website. |